



A FATHER'S WISH, A BIOETHICIST'S DILEMMA

JHU FACULTY MEMBER RECOUNTS THE AGONIZING DECISION HE HAD TO
MAKE FOR A PARENT UNABLE TO COMMUNICATE WITH THE WORLD.

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Dad was in the middle of making coffee when his heart stopped. From the next room of the house they shared in San Antonio, his new fiancée, Robin, heard the thud when he hit the ground. He was purple by the time she made it to his side.

Robin, a career nurse, immediately started CPR and called 911. When the EMTs arrived and took over trying to beat Dad's heart, she called my sister, who then called me. Sis was a mess, barely able to get out, "It's Dad. I think he's dying. He might be dead." Confused, I asked her what happened, and in a traumatized voice, all she could say was, "I heard it over the phone, Travis. *I heard them shock him.*"

When Robin arrived at the hospital that night, the attending physician told her it was time to let him go. Dad wasn't breathing on his own, so they had to put him on a ventilator. But there was no use continuing to breathe for him, the doctor explained. He had been gone too long. He wasn't coming back.

"That is *not happening*," Robin responded. "His kids are 1,000 miles away; they can't get here until the morning. Your job is to keep him alive until *they* can make a decision about withdrawing treatment." The doc fought her a bit but eventually yielded. In order to give him the best chance of surviving, they began what's called the Arctic Sun Protocol, which involves inducing hypothermia with the goal of slowing any brain damage.

By the time Sis and I landed in Texas on Dec. 30, 2019, all of us knew the score. Sis and Robin are both nurses, and I'm a bioethicist; we've all dealt with end-of-life cases, albeit in very different ways. The attending physician's pessimism was well-



grounded. Dad had been without a heartbeat for more than 20 minutes, and so any blood going to his brain had to be pushed there manually. But it's *really* hard to beat someone's heart for them—especially for that long—and so the default presumption in a case like my dad's is that his brain was starved for oxygenated blood. And without oxygen, brain cells die. That's anoxic brain injury. And everyone watching my dad assumed that had happened to some degree.

To what degree? Well, that part was impossible to tell this early, but too much would mean that he's never waking up; moderate amounts would mean that he might wake up but with severe impairments. That was basically all we knew as the Uber from the airport pulled up to the hospital, Sis and I got out, and I met my dad's fiancée for the first time.

When I walked into Dad's ICU room, the first thing I noticed was how connected he was to machines. The tube down his trachea was attached to one machine, the wires stuck to his chest attached to another, and the IV in his arm attached to many little machines stacked along multiple metal poles—each one regulating some medication that was keeping his body carefully balanced in its precarious state.

The first couple of days were awful and confusing. Here we were: three professionals who have fairly significant knowledge about and access to health care, and we were lost. The number of doctors who came through was overwhelming, and they all gave different reports on my dad's status. While they all agreed that he'd suffered a major cardiac event, there was no agreement concerning what kind of event nor what his prognosis was. Indeed, it was difficult to even find someone to talk about prognosis. Each specialist who came in chirpily reported that some specific organ was doing just fine.

So, everything looked OK; except for the whole "heart stopping" and "being in a coma" thing.

The coma was something else to process. I had always imagined that a coma is what someone enters when their brain shuts off and doesn't come back online. But we didn't actually know if Dad's brain was offline of its own accord. We

couldn't because he was hypothermic and on the ventilator, so he *needed* to be in a coma. They sedated him with propofol and benzodiazepines and threw in opioids for good measure. Many of his ribs were broken, and if he could feel anything, we wouldn't want him to be in pain. So, we didn't know whether his coma was just medically induced or the result of catastrophic brain injury.

The question that quickly came to define that first week was this: How likely was Dad to wake up again? Or, more important for us: How likely was he to wake up again *as Dad*? Obviously, that would be an important question for anyone in this situation, but it was given particular urgency by the fact that our very strange (and quite morbid, we always thought) father had very strong end-of-life preferences. He had made sure to tell me and Sis from the time we were young children that if we ever allowed doctors to impose life on him when he had diminished capacity, he'd die eventually and then come back to haunt us.

Seriously.

"Pull the plug," he'd tell his young children. And while the teenage versions of ourselves liked to tease him that we'd be only too happy to do so, his prescient insistence on not being forced to live if he wasn't himself haunted us in a quite literal sense as we came to understand the situation.

Getting our question answered, however, turned out not to be straightforward. Several days into our round-the-clock vigil in my dad's ICU room, we asked the attending physician his thoughts about prognosis, pushing him to prepare us for reality. He seemed annoyed. "Look, your dad is alive, which is impressive. His body is doing relatively well, so you just need to take this one day at a time and see what happens."

I wasn't pleased with his tone. "I get that. But you need to understand: My dad *does not* want to wake up with diminished capacity. He's told us this his whole life. So, our question for you is, How aggressively should we be working to keep him alive? Should we sign a DNR?"

The attending physician looked surprised. A DNR—or Do Not Resuscitate order—prevents clinicians from attempting CPR or defibrillation should a patient's heart stop. As his children, if we signed a DNR, the hospital would be required to let Dad die if he coded—if his heart stopped—again. And since we still didn't know what had

gone wrong with his heart, that was a very real possibility. The doc suggested that we weren't there yet and that we should just give him time.

The problem was that giving him time was making the decision to continue to work toward the goal of Dad waking up, even if that meant waking up in a state he feared. Trying to get more information risked putting Dad in the position he least wanted: alive, but with severe cognitive impairments.

My sister was frustrated with the attending's attitude and response. Being a nurse, though, she realized he wasn't the only avenue for information. She waited until she was alone in the hospital room with our favorite nurse—a sweet young man who had been an incredible comfort those first few days—and she approached him.

"I need to ask you a question," she began. "Nurse to nurse—professional to professional. Can we do that?" He looked around to the empty room and nodded.

"If this was my patient, would I ... would I feel sorry for him?"

Our nurse looked straight at her and responded with one word. "Yes."

Sis took a breath. "If this was your dad, would you sign a DNR?"

Slowly, but confidently, he again responded: "Yes."

"OK then." She knew it was time to start what could be a slow process. "Can you put in the order to change my dad to DNR? Just so the paperwork is ready if we decide to make that call?"

The nurse nodded compassionately and got to work.

Starting the process to change Dad's code status did not, however, commit us to going through with it, and we still wanted all the information we could get. We kept asking questions, and later that day we finally found our hero: the hospital neurologist, whose entire job was to help us figure out the thing that Dad would care most about—what shape his brain was in and what that meant.

When he first came in, he sat all three of us down and taught us Neurology 101, with a focus on anoxic brain injury. He explained what happens when your heart stops beating, how the neurons die, and the degree to which brains can heal from these injuries. And when he finished,

he patiently answered our questions and listened to our concerns.

Although we wouldn't have a clear picture of what was going on "under the hood" until Dad was thawed out and could get an EEG test of brain activity, the neurologist was willing to tell us what he expected to happen.

Plausible scenario: He never wakes up. His brain didn't get a full oxygen supply for a really long time. He might already be gone, and we just don't know it. "If that happens," he said, "you'll have to decide when to take him off the ventilator, and when we do, his body will catch up with his brain and he'll die." He said it matter-of-factly but also softly and kindly.

Equally plausible scenario: He wakes up. It's slow and it's hard. His brain is functioning but at diminished capacity and in new and different ways. He'll have to learn to do many things again, like walking, but maybe also speaking. "It would be impossible to predict how much ability he would eventually regain, but it wouldn't be everything, and it would take years," he told us. Sis and I were immediately tense. If we let that happen, he'd heal as much as possible and then kill us.

But there was one other possible scenario: He wakes up, and within three months, he can walk and talk and is on his way to a fairly full recovery. While explaining this, the neurologist looked at us closely. "I should emphasize that this is possible—not that it is what I expect. But then again, most hearts don't stop beating right in front of an experienced nurse."

So we had a little hope, but mostly fear. I slowly and carefully asked the question Sis and I were both thinking: "So, you've heard us talk about our dad and his wishes. And now we've heard the prognosis. It sounds to me like among the most likely outcomes is the one he fears most." I paused and looked at Sis. She nodded. "We're just asking your professional opinion: Does it seem respectful of his wishes to sign a DNR?"

He took a breath but didn't seem particularly uncomfortable with the question. "Yes. Given what you've told me—given who this guy seems to be—I think that's a reasonable decision. If his heart stops again, the prognosis gets worse, not better. It sounds like he might not want to come back from that."

I exhaled the breath I felt like I'd been holding for days. Sis did the same. We looked at each other and nodded.

As the older of the two of us, Sis was officially the health care proxy, and so a little later that day, she signed the form, and Dad got a new bracelet with the capital letters, D-N-R. No more heroic measures; no more trying to save a body attached to a dying brain. If Dad's heart stopped again, they would have to let him go.

Those first days in the hospital were morally excruciating. Every day that went by, our inaction constituted an action. By allowing the hospital to keep treating our dad, we worked toward the eventual goal of him waking up. But of course, his waking up might not be a good thing.

I felt like a coward. We were taking this huge risk, but there never seemed to be a way to change course. The passing of time kept adding moral weight to our previous decisions, and so each day, it felt more wrong to rethink Dad's treatment plan. We didn't withdraw care on Tuesday; so if he survived until Wednesday, why would we withdraw care then? In fact: As soon as the team began the Arctic Sun Protocol, the treatment plan had momentum. We felt immediately like passengers rather than drivers of his care.

I thought about all the times I had taught end-of-life cases in bioethics courses and how neat and tidy they always were. They were designed to be difficult owing to some moral dilemma or constraint: Perhaps there was disagreement among family members, or between family members and the care team regarding what to do. But the radical uncertainty of life in the ICU was never part of the cases I taught.

The lie in all my thinking about the end of life was in believing that I would understand what is, in fact, happening sufficiently to reason about what I should do in response. But this wasn't a case study that had all the relevant information. My dad "didn't want to come back not as himself." But what did it mean to not be himself? Did that include having modest trouble with fine motor skills? Having a worse memory by some percentage? Some slurred speech? Where was the line that he would object to crossing?

And then, crucially, What were his odds of crossing that line?

We didn't know the answers to any of those questions. But we had to make decisions anyway. So we did. We would try to wake up Dad's body and see whether he was still in it.

At the end of Dad's first week in the ICU, Sis and I took a break. She needed to check in on her family, and my daughter was turning 6. Dad needed to be thawed out, which would take a couple of days, after which the health care team could start with ventilator weaning trials, to see if he could breathe on his own. In truth, we had come to terms with the fact that he probably wasn't coming back, and so we were going home—her to Indiana, me to Maryland—to see family and gather strength for the terrible work ahead of us. Which made the phone call I received from my sister the day after I got home all the more surprising.

"Trav, *He's awake*. He's [expletive] talking!"

I didn't know how to respond. I was afraid I was misunderstanding. "What do you mean?" I carefully asked.

Sis, crying now, said, "I just sent you the recording. Listen!"

My phone dinged. I took it away from my ear to pull up the audio message and press play. A woman whose voice I didn't recognize asked, "And who is that?" To which a decidedly groggy but definitely identifiable Dad responded, "It's Michael, Robin's son."

I dropped the phone, put my head in my hands, and sobbed.

Waking up from a coma isn't like it is in the movies. Dad didn't go from unconscious to sitting up and having full conversations; he was a mess. Michael (correctly identified by Dad in the recording) picked Sis and me up from the airport when we arrived back in San Antonio. He had been an incredible help throughout the ordeal, and now he tried to prepare us.

"You need to be ready: Your dad is awake and sometimes seems like himself, but he's also not all there yet." He paused. I was confused. "What

I mean is: He's hallucinating. He doesn't understand that he's not allowed to get up yet. He's a bit of a Houdini, actually—if you leave him alone, he'll try to bolt out of the bed. So someone has to be with him at all times."

I was lost. "What do you mean? I don't get it."

Michael replied: "Look, I'm just trying to prepare you." He paused, and then gently: "He needs babysitting."

I was mortified—suddenly sure that our greatest fear was coming to pass. There had been so much celebration around his waking up, around his ability to talk immediately; we had already labeled it a miracle. Was our joy premature?

For as long as I live, I will never forget the moment I walked back into his ICU room. Instead of comatose, hooked up to a ventilator, there was my dad: awake and talking. When he saw me and Sis, all three of us burst into tears, and we rushed to opposite sides of his bed to hug and kiss him while we all bawled together.

But even in that initial moment of joy, I was registering some profound strangeness. Dad was ... *squirming*, for lack of a better word. As he saw us and was overcome with emotion, he thrashed his legs about and rocked side to side. After we got our initial tears out and could look at each other and talk, he was coherent but didn't stop moving. The strangeness of his movements was exacerbated by moments when his agitation would cause him to breathe too hard, and all his broken ribs would send shock waves of pain through his torso, making him search for a pillow to clutch to his chest while he entered a fit of coughing.

The distressing image got worse as we all calmed down and tried to talk about the terrible events of the past two weeks, and he would randomly bolt his attention to the hallway door and interrupt whoever was speaking by saying, "There! There's the mouse! See it running back and forth?" Each time, we would calmly explain to him that he was hallucinating, but he was frustrated that we didn't believe him.

In addition, we quickly came to understand Michael's "Houdini" warning. Any time Dad got too restless or needed to go to the bathroom, he would suddenly bolt upright in his bed and announce that he was leaving. Of course, he was both a terrible fall risk and connected to a dozen machines, so he really could not be allowed to

stand. No matter how many times we explained this, though, he would pull it again.

ICU delirium, we were told. Common for patients coming off ventilators but difficult to fully explain. Was it related to anoxic brain injury? The medications he had been on for more than a week? A combination, or something else?

Whatever it was, it was awful. And haunting. He didn't sleep for days, and so someone had to be at his bedside, awake, 24/7, which means we had front-row seats to some of the worst suffering I've ever seen. He was in pain, in serious cognitive distress, confused, and being assaulted by the strange physical and emotional symptoms of whatever he was going through. As the days went by without real rest, the symptoms worsened, and the gratitude of waking up began to turn to bitterness at the situation he woke up to.

On the second night back in San Antonio, it was my turn to take the graveyard shift, so I was sitting with Dad, talking, playing soothing music, trying to get him to rest, when he suddenly sat bolt upright and swung his legs off the bed.

"OK, Trav. I need to use the restroom. Help me up."

Exasperated, I planted myself squarely in his way. "Dad. You know you can't get up."

Conspiratorially, he whispered, "Come on, Trav. No one's here. You know I can do this. Now get out of my way." And then he *really* tried to stand up. Against my hands on his shoulders, I felt the pressure of a grown man—incapacitated, sure, but 6-foot-1 and solid—and I had to stand to hold him down.

He moaned as he gave up against my restraint. He wasn't conspiratorial anymore; he was angry. "Trav. *Out of my way.*"

His twitching and squirming suddenly got worse as he lost control of himself. He tried to force his way past me, and I started to plead with him: "Dad. Don't make me do this. Please, Dad. I can't let you get up. You'll hurt yourself." I was losing my composure, but he was not getting past me.

And then he was out of energy. He collapsed back onto the bed, legs hanging off, and he started crying. He lay there, rocking back and forth, miserable, sobbing, trying to turn away from me but twisted up by the weight of his dangling legs.

And then he said it. The thing I had feared from the beginning. "I had such a good life. And

now it's gone. How did this happen?" The sobs made him cough, and the coughing racked his body with pain. Over the course of a minute, he caught his breath, gathered his energy, and looked at me. "Why did you bring me back?"

I absorbed his anger but didn't respond. Instead, I carefully lifted his legs back onto the bed, grabbed the sheets, and pulled him back up to a normal position. And then I looked straight at him while he tried to avoid my gaze. "Dad." My voice was broken. "I know this is terrible. Your body, and your brain—they feel broken. They turned on you. But *it will get better*." I took a deep breath. "Do you believe me?"

Dad looked away, ashamed. "I believe you, Trav. I'm so sorry."

I hugged him and laid my head on his shoulder. "You have nothing to be sorry about."

But the words echoed: *Why did you bring me back?*

My dad not only survived his life-threatening arrhythmia, he recovered. Fully. I can't explain to you how remarkable this is. He was a celebrity in the hospital on the day he took his first steps—less than a week after being taken off a ventilator. Nurses and doctors came to see him as he slowly emerged from his delirium and returned, bit by bit, to his old self, telling him that he was a miracle.

I waited several days to start the conversation I wanted to have with him. When we finally got him moved out of the hospital and back home, we sat out on their patio and breathed fresh, nonhospital air. He couldn't stay awake very long between naps, and he still wasn't quite all there all the time; much of the time he was groggy, and his speech would slur. So I waited until he had some peak moments—when he was fully awake

A CURE FOR COMA?

Researchers at Johns Hopkins and elsewhere aim for better diagnosis, treatment, and outcomes for a condition that still mystifies.

Terry Wallis had been unable to respond to the world since 1984, when the truck he was riding in veered off an Arkansas bridge and crashed, tires up, into the creek bed below. Wallis spent two weeks in a coma, a state of prolonged unconsciousness, then lived most of the next 19 years in a minimally conscious state in which he could not communicate with words or gestures. But in 2003, at the age of 39, Wallis surprised both doctors and his family with his first word—"Mom"—followed by many others. Studies later found that Wallis' brain had continued to repair itself. Tests done 18 months after he emerged showed that Wallis had regained some motor function, strength, and fluency of speech, while brain scans showed more connectivity in damaged parts of the brain.

While many considered Wallis' recovery a miracle, those 19 years in between produced an interminable stretch of questions without good answers. For one, what was Wallis aware of when he appeared not to be responding? Even today, a coma diagnosis is accompanied by uncertainty,

says Jose Suarez, a professor of neurology at the Johns Hopkins School of Medicine and director of the Division of Neurosciences Critical Care.

"Families want to know: Is he or she going to wake up?" he says. And, if their loved one does wake up, what will their life look like?

Here's what we do know: A coma can be caused by traumatic brain injury (TBI), stroke, cardiac event, and complications from other illnesses, including COVID-19. Comas can also be induced intentionally to give the brain time to heal until swelling and pressure—which can cut off blood flow to the brain—can recede. But the balance between when a coma is helping the body and when the person is tipping toward decline is unclear. And even though patients in a coma can be kept alive for years, very little is known about what's going on under the surface.

All of this uncertainty can lead to a nihilistic attitude toward coma that's prevented us from learning more about the condition, Suarez says. "People immediately assume that just because you're in a coma, you're not going to do well, and

after a nap, and before the exhaustion started to set in. And then I asked him my question.

“Dad, you understand everything that happened to you now, right? You understand how bad things were, and what the odds were like?”

He turned serious. “I think I do, yeah. I know it was pretty bad.”

“And you know how things might have turned out?” I wanted to make sure he really understood.

“Well, I guess I might never have woken up. Or maybe I wouldn’t have been able to do much of anything for myself. Yeah, I think I get it.”

He got it.

“OK. So here’s my question.” I paused. “Did we do the right thing?”

He was quicker than I anticipated. “I don’t know, Trav.” It was a brutally honest but totally reasonable response.

He chuckled. “I mean, I’m glad to be alive. There’s so much I want to do, and I’m happy to be here. But I understand maybe it wasn’t going to end this way. You and Sis were put in an impossible situation.” He stopped for a while. I thought maybe he was getting tired and fading off, so I just let it hang. But then he continued. “Maybe this is one of those cases where you can only do the best you can, and you either get lucky or you don’t? If you had decided to pull the plug, I would understand that. It would have been in accordance with my wishes. Since I got lucky? I’m rather glad you didn’t.”

He smiled. I smiled. It was enough.

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therefore we should probably de-escalate care.” But by withdrawing care, health care providers don’t learn whether people will continue to survive or improve. “We’re essentially cutting off the natural history of the disease.”

But what if coma were considered, like diseases, something that could be treated? Launched in 2019 by the Neurocritical Care Society, the Curing Coma Campaign is the first to address coma as a treatable medical issue, bringing together researchers from Johns Hopkins and around the globe to better understand the condition and improve outcomes for those like Wallis, who died this spring at 57. The campaign has hosted two conferences and an annual World Coma Day, with members publishing original research on the topic. Beth Slomine, co-director of the Center for Brain Injury Recovery at the Kennedy Krieger Institute, says that the campaign aims to convey that individuals who have experienced coma can indeed recover, while its researchers work to develop new strategies for diagnosis and treatment.

In particular, the Curing Coma effort wants to explore how biomarkers, such as molecular and cellular markers shown under brain scans, can indicate neurological health. These tools help health care providers make earlier diagnoses and understand both the current level of a person’s consciousness and how they might be responding to interventions, such as medications or noninvasive brain stimulations, two approaches that are under study.

For Suarez, the true challenge underlying coma research is understanding consciousness itself. Consciousness has been explored by scientists, philosophers, and artists for hundreds—if not thousands—of years and may have an even bigger question beneath it: What does it mean to be human? While this question may always be with us, the Curing Coma Campaign aims to help coma patients and their families find the answers that are within reach. — **Cameron Walker**